



DOWN SYNDROME HEALTH CARE GUIDELINES

(Based on “Health Supervision for Children with Down Syndrome” as published in *Pediatrics*)

Infant (1 - 12 Months)

- Chromosomal karyotype; genetic counseling, if not already done.
- Discuss chances of having another child with Down syndrome.
- Use typical growth charts from Centers for Disease Control (CDC), available at www.cdc.gov/growthcharts. Use weight/height assessment, as well.
- Radiographic swallowing assessment if marked low muscle tone, slow feeding, choking with feeds, recurrent or persistent respiratory symptoms, failure to thrive. Consider feeding therapy referral, if needed.
- At 1 year of age begin to check hemoglobin count annually. Include (a) ferritin and CRP or (b) reticulocyte hemoglobin if there is a concern for a diet low in iron or if hemoglobin < 11g.
- Eye exam for cataracts. Ophthalmology referral to assess for strabismus, nystagmus and cataracts.
- Delayed or irregular dental eruption, hypodontia is common. First dental visit by 1 year.
- If constipation present, evaluate for limited diet or fluids, hypotonia, hypothyroidism, gastrointestinal malformation, or Hirschsprung disease.
- Discuss cervical spine positions, especially for anesthesia or surgical or radiologic procedures.
- Review signs and symptoms of myopathy. If myopathic signs exists, obtain neck X-rays (C-spine).
- Thyroid function tests at 6 and 12 months(FT4 and TSH).
- If a heart condition is identified, monitor for signs and symptoms of congenital heart failure, subacute bacterial endocarditis prophylaxis (SBE), as indicated.
- Well child care: immunizations including influenza.
- Newborn hearing screen follow-up and assessment by 3 months. Audiology evaluation at 6 months and every 6 months until “ear specific testing is accomplished and normal,” at which point hearing screens can be done on an annual basis.
- Review signs and symptoms for obstructive sleep apnea.
- Discuss Early Intervention, including speech therapy, and refer for enrollment in local program, if not done already.
- Apply for Supplemental Security Income (SSI), depending on family income.
- Consider estate planning and custody arrangements; continue family support.
- Discuss complementary and alternative therapies.
- Referral to local Down syndrome parent group or family support and resources, as indicated. Referral to NDSS.